



# Avery's Angels

## GASTROCHISIS FOUNDATION

To whom it may concern:

Please see below for a request for an official proclamation to declare July 30<sup>th</sup> an annual Gastrochisis Awareness Day in South Carolina. Gastrochisis is a birth defect which causes the intestines to protrude from the abdomen and is rapidly increasing in incidence. It should be noted that Avery's Angels Gastrochisis Foundation, the entity making the request, is based in Raleigh, NC and is the only nonprofit in the entire world specifically for gastrochisis support. Furthermore, July 30th is the date that Avery's Angels founder lost her son (Avery John Rauen) to gastrochisis at UNC hospital at only three months of age. As Avery's Angels Gastrochisis Foundation is working hard not only to support families experiencing gastrochisis but also to fund research to find the cause of this birth defect, a statewide proclamation would greatly help to secure potential investors for this goal. We hope with all sincerity that you will realize how important this observed day will be to South Carolina residents (and ultimately those in other states as well as we hope that in future years, additional governors will grant a proclamation for July 30<sup>th</sup> in their own states) and declare Gastrochisis Awareness Day on July 30<sup>th</sup> annually. Thank you so much for your consideration.

Whereas, there are 1 in 2229 individuals born with gastrochisis in the United States, and roughly the same number born in South Carolina annually;

Whereas, this disease may affect small numbers of people, gastrochisis affects many Americans;

Whereas, many Americans living with gastrochisis have serious and debilitating conditions that have a significant impact on the lives of those affected including but not limited to failure to thrive/slow growth, short bowel syndrome, multiple organ transplants, and long term feeding issues;

Whereas, individuals and families affected by gastrochisis often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment;

Whereas, the cause of gastrochisis is relatively unknown, patients and their families must bear a large share of the burden for things such as raising funds for research;

Whereas, hundreds of residents of South Carolina are among those affected by gastrochisis;

Whereas, an official Awareness Day proclamation is often the precursor to funding for research and other avenues of support;

Whereas, Avery's Angels Gastrochisis Foundation (AAGF) is organizing a nationwide observance of Gastrochisis Awareness Day on July 30, 2013, and every year thereafter;

Whereas, South Carolina resident – Kylie Grace Dixon- has slow weight gain and developmental issues due to side effects caused by gastrochisis. She suffers from constipation and has had numerous hospital visits that a 4 year old should not have to endure.

Whereas the founder of Avery's Angels son– Avery John Rauen –passed away from complications of his gastrochisis on July 30, 2009 at UNC hospital, and this date is to commemorate him and all others living with or deceased from gastrochisis;

Therefore, be it resolved that July 30, 2016, will be observed as Gastrochisis Awareness Day in South Carolina, and preferably henceforth in subsequent years.

Sincerely,

**Ashley Heath**

112 Crossings Blvd. Bluffton, SC 29910

If you do decide to declare July 30<sup>th</sup>, 2016  
as Gastroschisis Awareness Day, our family  
would love to present when you declare it.

We do understand though that you have a  
very busy schedule. We hope to hear from  
you soon. ♡

Sincerely,  
Ashley Heath

Contact info:

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May 8<sup>th</sup>, 2012.

- Day Kylie  
was born.



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may 14<sup>th</sup>, 2012.

Kylie had her  
closure surgery  
to place intestines  
back inside.



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